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ABSTRACT

The New Jersey State Department of Health, Gerontology Program, awarded grants to 32 adult day care centers statewide for the provision of specialized service for victims of Alzheimer's disease and related disorders and their caregivers. The primary goals of the programs were to reduce caregiver burden through providing social supports and to improve the management of dementia behaviors. An ongoing longitudinal study was initiated during the start-up phase of the grant period to examine the impact of adult day care on caregiver burden. Data were collected from a nonprobability sample of clients (N=30) with a confirmed diagnosis of Alzheimer's disease or a related disorder and their caregivers (N=30). Information was obtained using three instruments to measure the caregiver's behavioral status. Demographic data revealed social supports and health and social service utilization. Measurements were taken prior to admission into adult day care and quarterly thereafter over 12 months. Preliminary findings showed strong support for the hypothesis that the degree of burden experienced by caregivers of demented elders is reduced by participation in specialized adult day care programs. (Author/NB)

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CAREGIVERS OF DEMENTED ELDERS: THE IMPACT OF ADULT DAY CARE SERVICE ON REDUCING PERCEIVED DEGREE OF BURDEN

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CAREGIVERS OF DEMENTED ELDERS: THE IMPACT OF ADULT DAY CARE SRVICE ON REDUCING PERCEIVED DEGREE OF BURDEN. J. Eddowes, R.N.C. M.S.N. New Jersey State Department of Health, Gerontology Program, CN 369, Trenton, NJ 08625.

The New Jersey State Department of Health, Gerontology Program, awarded grants to 32 adult day care centers statewide for the provision of specialized service for victims of Alzheimer's disease and related disorders and their caregivers. Specialized program components target management of the client and support of the caregiver. The theoretical framework of this programmatic approach is based on S. Zarit's research which determined the most important predictors of caregiver burden are social supports and the ability to manage money and behavior problems. The primary goals, therefore, of these programs are to reduce caregiver's burden through providing social supports and improving the management of dementia behaviors.

This paper will summarize preliminary data from an ongoing longitudinal study initiated during the start-up phase of the Department of Health's grant period. The study examines the impact of adult day care on caregiver's degree of burden, which has not previously been investigated. The research hypothesis states that the degree of burden experienced by caregivers of demented elders will be reduced by participation in specialized adult day care programs. Data was collected from a nonprobability sample of clients with a confirmed diagnosis of Alzheimer's disease or a related disorder (n=30), and their caregivers (n=30). Information was gathered using three instruments to measure the caregiver's behavioral status. Demographic data revealed social supports and health and social service utilization. Measurements were taken prior to admission into adult day care and quarterly thereafter over twelve months. Analysis corresponded with the major research question guiding the study, as well as interrelational effects. Preliminary findings show strong support for the research hypothesis. Implications are given for public policy and service provision that would incorporate specialized components into existing programs and develop new programs realizing the potential for reducing caregivers' degree of burden.

Caregivers of Demented Elders: The Impact of Adult Day Care Service on Reducing Perceived Degree of Burden

INTRODUCTION

The development of adult day care programs in the last decade has been extensive with many programs emerging to provide services for populations with special needs. The demented elderly and their caregivers have most recently been targeted to receive such services. While the burden experienced by caregivers of the demented elderly has been extensively examined in recent years, few evaluations have been undertaken to determine the impact of specialized adult day care programs on the caregiver. The New Jersey State Department of Health, Gerontology Program, is currently examining the impact of adult day care on caregivers of demented elders perceived degree of burden.

Through a state appropriation of 1.1 million dollars to the Department of Health, awards were made to 34 adult day care centers statewide for the provision of specialized services for victims of Alzheimer's disease and related disorders and their caregivers. Primary goals of the grants were to develop model programs that would 1) provide aid to the caregivers and 2) provide therapeutic service rather than simply recreation/custodial care for demented elders. Program components designed to meet the stated goals were defined as the following: educational workshops for caregivers dealing with management of dementia, monthly support groups, access to ongoing counseling, information and referral services, intense 1:5 staff client ratio, individualized care plans, and daily programming that maximizes remaining capabilities and provides opportunities for success and esteem. The theoretical framework of this programmatic approach is based on Steven Zarit's research (1985), which determined the most important predictors of caregiver burden. These predictors are social supports and the ability to manage memory and behavior problems. It was anticipated therefore that caregivers' perceived degree of burden would be reduced by participation in these specialized adult day care programs.

METHODS

A longitudinal study was initiated during the start-up phase of this new initiative. Candidates for the study sample were those accessing day care service for the first time. Data was collected from a convenience sample of clients with a diagnosis of Alzheimer's disease or a related disorder (n=18), and their caregivers (n=18) who participated in these specialized adult day care programs. Information was gathered using three instruments selected for their high degree of reliability, validity, and their ease of administration. Registered nurses and social workers from the respective agencies administered the tools. Caregivers perceived degree of burden was evaluated using Zarit's Burden Interview (1985). Although norms for Zarit's tool have not been established to indicate mild, moderate, and severe degrees of burden, assessing the caregiver before and after an intervention yields a numerical value that indicates the degree of success or improvement in the caregivers' situation. Severity of clients' cognitive impairment was measured using Pfeiffer's Short Portable Mental Status Questionnaire (1975). Behaviors associated with dementia were clinically rated using the Haycox Dementia Behavior Rating Scale. A time

series design was utilized. Measurements using all three instruments were taken prior to admission into adult day care and planned for quarterly intervals thereafter for one year. Demographic data obtained through caregiver interviews during the intake process revealed social supports, and health and social service utilization.

FINDINGS

To date, 18 subjects have been enrolled in the study. Six of these 18 subjects have been dropped from the study, leaving 12 subjects on which to report preliminary findings. Of the 6 subjects dropped from the study, 3 were placed in long-term care facilities, 2 were moved to secondary caregivers out of the service area of day care, and one was hospitalized due to a cerebrovascular accident. Of the remaining client sample, 66.7% are female, 33.3% are male. The client ages range from 57 to 86 with a mean age of 76. All have a diagnosis of Alzheimer's disease. On admission, 50% were severely impaired and 50% were moderately impaired according to Pfeiffer's Short Portable Mental Status Questionnaire. The caregiver sample includes 67% female and 33% male. Analysis of caregivers' relationship to clients revealed that the majority are spouses (46.6%), 26.8% are daughters, 6.6% are sons, and 20% are other relatives. When employment of the caregivers was examined, it was found that 46% are retired, 26% are employed full-time, 20% are part-time, and the remaining 8% were unemployed.

On intake, the scores of the Haycox Dementia Behavior Rating Scale ranged from 1 to 32, with a mean of 12.3 of a possible 48, 48 representing the highest dementia behavior rating. The scores after the first quarter ranged from 6 to 32 with a mean of 13.8. The Wilcoxon T test showed no statistical significance in the mean scores from initial to first interval data collection. The mean score of the Pfeiffer's Mental Status Questionnaire on intake was 8 out of a possible 10, 10 indicating the most cognitive impairment. Scores ranged from 5 to 10 on intake and 4 to 10 after the first quarter. Four of the 12 clients scored higher after the first quarter, 2 scored lower, and 6 remained the same. The mean score after the first quarter was 7.9. Analysis showed no statistical significance in the mean scores from initial to first interval data.

The Burden Interview scores ranged from 24 to 65 on intake with a mean score of 34 of a possible 88, 88 indicating the greatest burden. Scores ranged from 8 to 65 with a mean of 31 after three months of adult day care. Comparison of the two means using the Wilcoxon T test proved statistically significant at the .05 level. Nine of the 12 subjects or 76.9 % had a lower score on the Burden interview after three months of adult day care.

DISCUSSION

Although clients' mental status and behaviors did not show a statistically significant improvement, caregivers' perceived degree of burden was significantly reduced after three months of adult day care service. These findings support the research hypothesis that specialized adult day care programs do reduce caregivers' burden.

Of clinical significance were staff reports of positive outcomes related to

administering the Burden tool via interview. The most commonly reported benefit was that the burden tool aided staff in identifying additional service needs. These services were then incorporated into the plan of care. In addition, staff indicated questions from the Burden tool enabled caregivers to recognize in themselves areas of particular burden. Once identified, the staff could assist family caregivers to effectively deal with them.

Also of clinical significance were reports from staff that initially, many caregivers were reluctant to relinquish a part of their caregiving responsibilities, often accompanying the clients through several hours of the program each day. In this initial service phase staff reported spending intensive time in 1:1 caregiver support and counseling activities. After two to four weeks caregivers appeared more confident in leaving the client at the program and began to take advantage of the personal time. Staff believed that caregiver participation in Alzheimer's support groups, and informal education and counseling aided in this adjustment.

An examination of the study sample's day care attendance revealed that actual service utilization was 30% lower than planned. Analysis to determine a correlation between actual service utilization and Burden Interview Scores did not prove statistically significant. These findings suggest that the knowledge of the availability of day care service, as well as the other components such as caregiver counseling, education, referral, and information serve to reduce caregivers' burden.

Reports from day care staff pertaining to the clients indicated that in a structured, safe, therapeutic milieu, much of their fear of failure and anxiety was allayed, and many disrupting and perplexing behaviors associated with Alzheimer's disease were controlled or significantly diminished. Data after only one quarter of adult day care did not support this observation as there was not a significant improvement in the Haycox Dementia Behavior Rating Scale. Although it is too early in the study to consider this data conclusive evidence of the impact of therapeutic programming on dementia clients mental status and behaviors, it is worth noting that while Alzheimer's disease and related disorders are progressive dementing illnesses, there was no statistically significant decline in the scores on the mental status exam and behavior scale. The impact of therapeutic programming on behavior and mental status over time will be determined more accurately by subsequent quarterly data.

The major limitations of this study are the sample size and lack of control group. While a time-series study design reveals rich data, it presents a series of methodological problems of which attrition is a major concern. In this study, attrition occured for several reasons. First, the client population is frail, with a high incidence of age associated impairments or illnesses which often result in an interruption of service utilization. Likewise, many caregivers are frail as 46.6% are elderly spouses. Second, primary caregivers are likely to change. Adult children were found to share the caregiving role by rotating their parent to each of their residences, frequently moving the client out of the day care service area. The third consideration in attrition is that according to the mental status

exam, caregivers did not access adult day care until the client was severely impaired, and the caregiver had nearly reached the end of their caregiving capabilities. We can only hope that this phenomenon of late admission to adult day care will change with the advent of more subsidized day care and greater recognition of day care as a component in the continuum of care for the elderly.

Future research should replicate this pilot study using a larger sample and a control group design. The use of an outside investigator to collect observational data would reduce the researcher bias potentially incurred by staff selectively recording client observations. Inquiries that evaluate and compare specific therapeutic approaches and interventions for their impact on caregiver burden are needed. The impact of other services such as in-home care should be compared to day care for their impact on the caregiver.

IMPLICATIONS

The findings of this study have implications for practice as well as public policy. Day care staff should be aware of the potentially significant role the program can play in aiding caregivers. Reducing caregiver burden can actually extend the period of time that he or she is able to carry out that role. This more often than not means a delay in long-term care placement. Public policy should support programs which utilize a client/caregiver centered approach with therapeutic components for each. More intensive client:staff ratios that are capable of handling the needs of clients and support of caregivers are necessary, as well as facilities that are equipped to manage clients through inevitable decline. These programs would be more costly than those which utilize a recreational approach. However, if these programs are able to prevent early institutionalization, they would render the continuum of care more cost effective.

Finally, we should consider the findings of this study encouraging. We need not feel that we have nothing to offer over burdened caregivers of demented elders. Tangible service and comprehensive supports offered through adult day care can have a positive impact on the caregiving experience.

Caregivers of Demented Elders: The Impact of Adult Day Care Service on Reducing Perceived Degree of Burden

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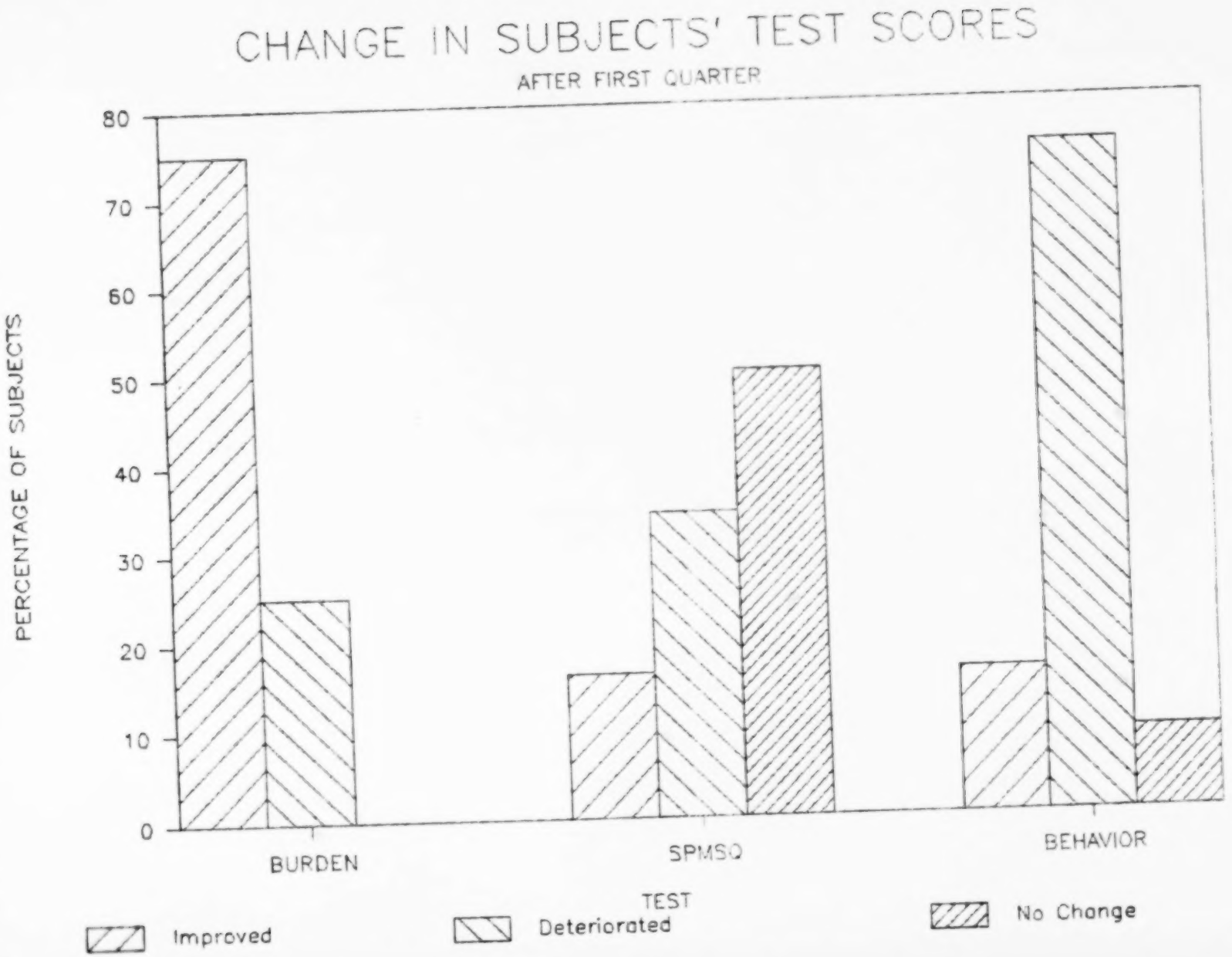
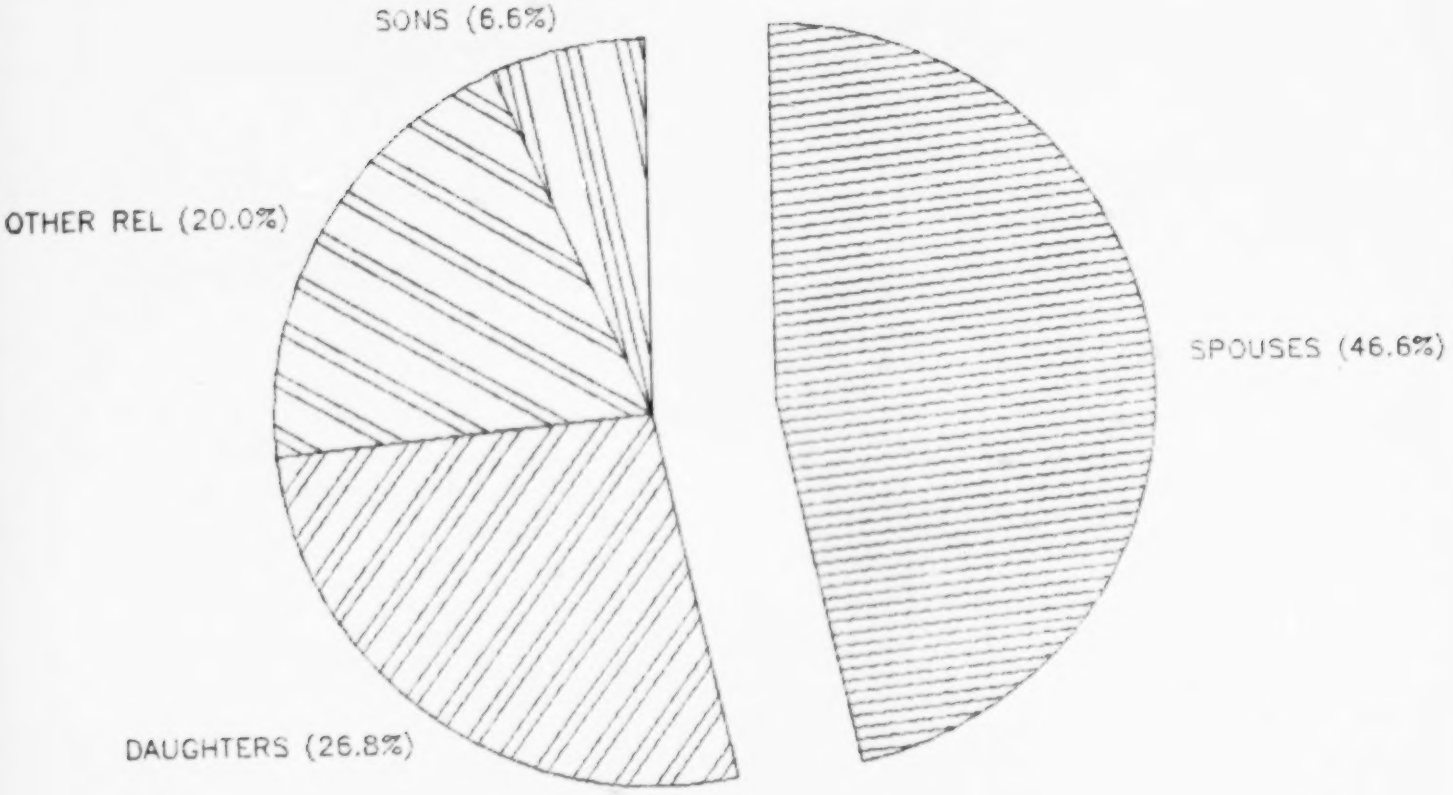

CHANGE IN SUBJECTS' TEST SCORES
AFTER FIRST QUARTER
PERCENTAGE OF SUBJECTS
80
70
60
50
40
30
20
10
0
BURDEN
SPMSQ
BEHAVIOR
TEST
Improved
Deteriorated
No Change

CAREGIVERS' RELATIONSHIP TO CLIENT



CAREGIVERS' EMPLOYMENT STATUS